Will you help MND patients rapidly access the first new treatment in 30+ years?

The only likely candidate to give us hope for the next 3-5 years?

Background

Patients United to End MND have been lobbying the Mirocals trial Consortium[1], leading neuroscientists and charities to speed up access to a new therapy, **low dose Interleukin 2**, that is likely to be confirmed soon, that significantly reduced the risk of death between 40% & 70% for up to 80% of all patients in the trial**.** This could be life-changing.

With confirmation of a successful outcome to the Mirocals trial hoped for soon, it's important MPs should be aware of the potential for a major public outcry in the media.

The trial drug is readily available as the brand Proleukin™ and is already used in the NHS to treat some forms of kidney cancer. Scientists are increasingly confident that at low dose, it can be of significant benefit to those living with MND.

What we know

1 - Proleukin™, is available at the right dosage for immediate delivery to UK hospitals.

2 - Many leading neurologists would prescribe Proleukin™ in the event of a positive outcome.

3 - Proleukin™ is relatively inexpensive, at less than £13k per patient per year.

4 - Administration & monitoring of Proleukin™ should not be burdensome.

5 - Proleukin™ is proven safe at low doses.

Why Proleukin™?

We emphasise Proleukin™ because of the likelihood that commercial considerations may promote the use of another, new, drug unlikely to be commercially available for several years. We note that:

ILTOO, a French company, has purchased the rights to the trial data to develop a new drug, known as a bio-similar. This is likely to take several years to be authorised, if ever, including a high likelihood of a further trial - this is simply unacceptable to patients.

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[1] https://www.mndassociation.org/research/clinical-trials/mirocals

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What can I do?

We urge MPs to support rapid access to low-dose Proleukin™ through the following pathways: NHS Specials, NHS Medicines Repurposing & full authorisation with a clear emphasis on the **fastest** routes.

Not only would rapid access through appropriate pathways be a huge lift for the MND community, it would also underpin the claims of UK to be a **scientific superpower** in the life sciences sector.

It's now 20 months since completion of the trial and 15 months since the promising top line results. Approximately another 3000 MND patients would have died in this time in the UK.

There is a growing concern some patients are now turning to obtaining the drug via private prescription and digging into life savings that they would prefer to use to make their lives more comfortable and to make memories with their loved ones. Not only does this create an obvious **health inequality**, but it also raises issues around the safe administration of the therapy.

We also ask MPs to request answers from the Consortium for transparency on due diligence carried out on its commercial contracts given that the trial was funded by EU and UK taxpayers' and charity donors' funds.

We continue to press the Consortium to answer our questions, to prepare for a positive outcome and to publish the results.

We urge MPs to help us get the TRANSPARENCY and LEADERSHIP patients deserve, speed the publication of the results and, above all, get us rapid access to the treatment.

We welcome the recent statement from MND Association, My Name5 Doddie Foundation and MND Scotland[2] (27/02/2024) which says

"In the event of publication of positive results of the full MIROCALS trial, we will be united with healthcare professionals in assisting our community with access as appropriate and make every effort to get people with MND access to low-dose interleukin-2 / aldesleukin (Proleukin, the form of the drug used in the trial) through all available pathways"

Charities and patients are #United2EndMND

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[2] https://www.mndassociation.org/media/latest-news/mnd-charities-update-mirocals-data